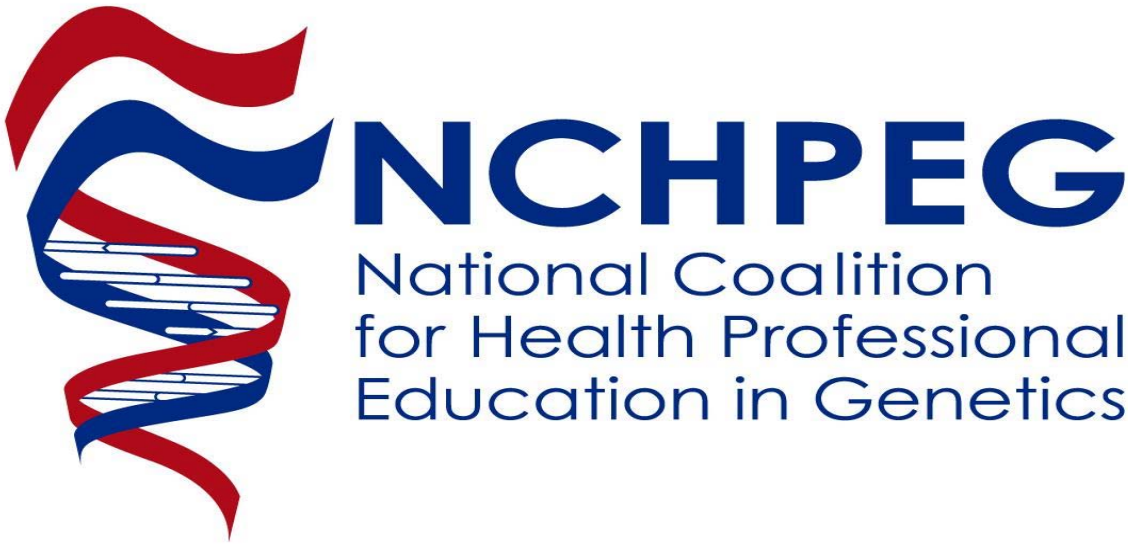
# Core Competencies in Genetics for Health Professionals




**Third Edition**

**September 2007**

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Dear Colleagues:

On behalf of the National Coalition for Health Professional Education in Genetics, we are pleased to provide this third edition of *Core Competencies in Genetics for Health Professionals*. Much has transpired scientifically since the original publication of the Core Competencies in January 2001, and the importance of education about genetics and genomics has increased as a result. The second edition of the Competencies, published in 2005, highlighted their widespread use as health professionals around the world integrated genetics and genomics into a broad array of educational programs.

We owe a continuing debt of gratitude to Dr. Jean Jenkins, National Human Genome Research Institute, for her guidance of the working group that produced the Core Competencies and for her ongoing efforts to collect information about their use. Dr. Jenkins; Cindy Prows, MSN, Cincinnati Children's Hospital; and Dr. Preston Reynolds, Society of General Internal Medicine, were instrumental in the production of this new edition, which has reduced the set to a list of 18 essential competencies.

NCHPEG has benefited considerably from extensive feedback about the Competencies, and we invite continued comment from the community at large. We hope you will let us know about your work as you draw upon the collective expertise of your colleagues to implement the Core Competencies in Genetics in the manner most appropriate to your own discipline.

Sincerely,

Francis S. Collins

Joseph D. McInerney

Francis S. Collins, MD, PhD
Chairman, Board of Directors

The National Coalition for Health Professional Education in Genetics (NCHPEG) is a non-profit organization whose mission is to promote the education of health professionals and to provide access to information about advances in human genetics to improve the health care of the nation. Each member organization appoints a representative to NCHPEG, and individuals from this interdisciplinary group work together to develop educational programs intended to achieve NCHPEG's goals.

One of NCHPEG's first priorities was to identify core competencies in genetics that are essential for all health professionals. Implicit goals in seeking this consensus among NCHPEG members were to: (1) validate the importance of a basic foundation in genetics for health care, (2) foster the use of common terminology, (3) increase the consistency of genetics-education efforts across the disciplines, (4) promote active discourse about the relative role of different professions in the provision of genetic services, and (5) reduce duplication of effort.

The core competencies working group, which originally consisted of 27 members, convened in 1997. After much input, discussion, and revision, the NCHPEG steering committee approved a set of 44 core competencies in February 2000, and the original publication appeared in 2001 (Core Competencies Working Group 2001) . The competencies themselves remained unchanged in the second edition, which also added information about the impact of the Competencies in the four years following their original publication.

This third edition is the result of more than 18 months of work to redefine that core set of competencies in genetics. The document reflects the experiences of those who have used the Competencies, as well as continual review by our membership and Board of Directors. If you have questions about this document or would like information about NCHPEG, please contact:

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# PURPOSE

Competence now serves as the dominant framework for the education of health professionals, replacing a centuries-old model of knowledge-based learning and testing. This new imperative requires that health professionals master not only the knowledge base of their discipline, but also that they understand why, when, and how that knowledge should be applied to improve health outcomes for their patients (Leach 2001; Batalden et al. 2002; Carraccio et al. 2002; Leung 2002; Foss et al. 2004; Guttmacher & Collins 2005).

The long-term goal for development of a set of core competencies in genetics is to encourage clinicians and other professionals to integrate genetics knowledge, skills, and attitudes into routine health care, thereby providing effective and comprehensive services to individuals and families.

NCHPEG recommends that all health professionals possess the core competencies in genetics identified in this report so they can integrate genetics effectively and responsibly into current clinical practice and education of health professionals.

## Background

Since the appearance of the core competencies in early 2001, the world has witnessed, among other advances in genetics and genomics, publication of the complete sequence of the human genome, the growing use of microarray technology to determine gene expression and refine treatment in selected cancers, and the increasing application of pharmacogenomics to develop new drugs and to tailor the use of those already on the market (ACCP 2004; Guttmacher et al. 2004; PMC 2006). The sheer volume of new information now at the disposal of biomedical researchers and health care providers is transforming our understanding of disease processes – including those of common, chronic diseases such as cancer, diabetes, and mental illness (Diabetes Genetics Initiative 2007; Wellcome Trust Case Control Consortium 2007; Zuchner et al. 2007) – and is changing the delivery of health care (Wright & Hart 2002; Jenkins & Lea 2005; Korf 2005). Public health agencies increasingly will apply genetic insights to the analysis of disease in populations and to the targeted introduction of strategies for disease prevention (Khoury et al. 2000; CDC 2001; Khoury 2003; CDC 2003), and will continue to work with the private sector to ensure the quality, efficacy, and safety of genetic tests (Burke 2004; Burke & Zimmern 2004; Gudgeon et al. 2007). The general public, empowered by access to information on the World Wide Web, grows better informed each day about genetics and genetically based health care. Increasingly, health care providers – regardless of specialty, role, or practice setting – will face questions about the implications of genetics and genomics for their patients. And yet, the rapid pace of the science and the relative paucity of professional training in genetics continue to leave many clinicians without satisfactory answers to genetic questions from their patients (Reynolds & Benkendorf 1999; Rackover 2007; Baars 2007; Guttmacher et al. 2007; Harvey et al. 2007).

# IMPLEMENTATION

NCHPEG believes it is essential that individuals and organizations responsible for training and continuing education of health professionals adopt these competencies and integrate genetics content into ongoing education. Although there has been much progress in the design and implementation of courses in genetics within all health professions since the original publication of the Core Competencies, the need remains for continued commitment by all educators to incorporate genetics information into all levels of lay and professional education.

Enhanced competence in genetics will help health professionals and the public respond to the changing demands of health promotion and disease diagnosis and management. Even today, no one can predict with certainty how genetically based health care will be organized or who will provide the bulk of genetic services when genetics is fully integrated into the health care system. Nonetheless, many people recognize that health professionals involved in the *direct* provision of genetic services often require additional training to achieve an appropriately higher level of competence.

The original set of Core Competencies in Genetics Essential for All Health Professionals first appeared amid great public and professional interest in genetics, largely the result of significant media attention surrounding the Human Genome Project. Consequently, the Competencies generated considerable dialogue within the genetics community and within the health professions more broadly. Some in the genetics community were concerned that broad adoption of the Competencies would result in the transfer of all genetic services to providers not formally trained in genetics, thereby obviating medical genetics and genetic counseling as specialties. Others in the genetics community viewed the Competencies as unrealistic and unattainable by non-geneticists. Some non-geneticists concurred and wondered whether their intent was to turn all health-care providers into genetic specialists. Those questions became part of the larger debate about the future of genetically based health care, one more variable in the complex mix of factors influencing a health care system in rapid flux.

The second edition of the Core Competencies sought to capture their impact by documenting their dissemination through literature citations and access to print and Web-based copies; and by describing through case studies their use by educators around the world in the design and implementation of genetic courses for nearly every health profession. The examples published in the second edition indicated that different disciplines applied selected Competencies as they deemed most appropriate for their audiences – an approach that NCHPEG supports.

The NCHPEG Core Competencies remained a work in progress, and a number of member representatives advocated for a shorter list. A smaller working group was established to undertake this project. Dr. Jean Jenkins and Dr. Preston Reynolds, both of whom were involved in development of the original set of Competencies and in the publication of the second edition, were joined by Cindy Prows, MSN, co-chair of the NCHPEG Content and Instruction Working Group. This small group surveyed a set of individuals who had used the Competencies in developing new genetics curricula, asking the respondents to rate each of the original 44 Competencies as "essential" or "non-essential." Survey results demonstrated that this group of educators considered 14 of the Competencies most important. The project team then solicited input from the NCHPEG Board of Directors and from the NCHPEG member organizations and their constituents. The list of 14 was expanded to 18, with refinement of wording to capture what both geneticists and non-geneticist health professionals now consider to be an essential set of competencies in genetics.

NCHPEG's Core Competencies in Genetics –September 2007

BASELINE COMPETENCIES

| ***At a minimum, each health-care professional should be able to:*** |
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| ***a. examine one's competence of practice on a regular basis, identifying areas of strength and areas where professional development related to genetics and genomics would be beneficial.*** |
| ***b. understand that health-related genetic information can have important social and psychological implications for individuals and families.*** |
| ***c. know how and when to make a referral to a genetics professional.*** |

1. KNOWLEDGE

***All health professionals should understand*:**

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| 1.1 basic human genetics terminology. |
| 1.2 the basic patterns of biological inheritance and variation, both within families and within populations. |
| 1.3 how identification of disease-associated genetic variations facilitates development of prevention, diagnosis, and treatment options. |
| 1.4 the importance of family history (minimum three generations) in assessing predisposition to disease. |
| 1. 5 the interaction of genetic, environmental, and behavioral factors in predisposition to disease, onset of disease, response to treatment, and maintenance of health. |
| 1.6 the difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation). |
| 1.7 the various factors that influence the client's ability to use genetic information and services, for example, ethnicity, culture, related health beliefs, ability to pay, and health literacy. |
| 1.8 the potential physical and/or psychosocial benefits, limitations, and risks of genetic information for individuals, family members, and communities. |
| 1.9 the resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities. |
| 1.10 the ethical, legal and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment). |
| 1.11 one's professional role in the referral to or provision of genetics services, and in follow-up for those services. |

## 2. SKILLS

***All health professionals should be able to:***

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| 2.1 gather genetic family history information, including at minimum a three-generation history. |
| 2.2 identify and refer clients who might benefit from genetic services or from consultation with other professionals for management of issues related to a genetic diagnosis. |
| 2.3 explain effectively the reasons for and benefits of genetic services. |
| 2.4 use information technology to obtain credible, current information about genetics. |
| 2.5 assure that the informed-consent process for genetic testing includes appropriate information about the potential risks, benefits, and limitations of the test in question. |

## 3. ATTITUDES

**All health professionals should:**

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| 3.1 appreciate the sensitivity of genetic information and the need for privacy and confidentiality. |
| 3.2 seek coordination and collaboration with an interdisciplinary team of health professionals. |

Competencies that delineate the components of the genetic-counseling process are not expected of all health-care professionals. Health professionals should, however, be able to facilitate the genetic-counseling process and prepare clients and families for what to expect, communicate relevant information to the genetics team, and follow up with the client after genetic services have been provided. Those health professionals who choose to provide genetic-counseling services to their clients should be able to perform all components of the process, as delineated at http://abgc.iamonline.com/english/View.asp?x=1529.

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